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Missed opportunities for physical activity management at key points throughout the chemotherapy pathway for colorectal survivors: An observational interview study.

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Compliance with Ethical Standards

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee Research Ethics Committee (15/EE/04/34) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards [1]. Informed consent was obtained from all individual participants included in the study.

ABSTRACT

Purpose

Physical activity (PA) is central to self-management for people with colorectal cancer (CRC) to support health behaviour and function secondary to cancer treatment. However, there is limited evidence on how health professionals (HPs) promote PA during cancer treatment. This study aimed to investigate how and when PA is promoted throughout the chemotherapy pathway among colorectal cancer survivors.

Methods

A qualitative study was conducted with adults with CRC receiving chemotherapy at a large cancer centre. Cross sectional, observation of clinical consultations was conducted at four points during the chemotherapy pathway: prior, midpoint, final cycle and 8 weeks following chemotherapy. Following completion of treatment, audio recorded, semi-structured interviews were conducted with patients and HPs and transcribed verbatim. Codes and themes were identified and triangulated from all the data using Framework Analysis. Observational themes are reported and complimented by interview data.

Results

Throughout the chemotherapy pathway (pre, midpoint, end) many opportunities were missed by HPs to promote PA as a beneficial means to maintain functioning and ameliorate cancer treatment side-effects. When discussed, PA levels were used only to determine fitness for future oncological treatment. No PA promotion was observed despite patients reporting low PA levels or treatment side-effects. Post-treatment, PA promotion was more routinely delivered by HPs, as evidenced by problem-solving and onward referrals to relevant HPs.

Conclusion

PA promotion was largely absent during treatment despite it being a key component of patient self-management following treatment. This suggests considerable missed opportunities for HPs to provide cancer survivors with PA evidence-based interventions. Further research is necessary to identify how best to ensure PA is promoted throughout the cancer journey.

Implication for cancer survivors

These findings suggest many may not be receiving support to be physically active during treatment.

K**eywords**

Self-management; colorectal neoplasms; qualitative; physical activity

INTRODUCTION

By 2030, global cancer incidence will reach 26 million [2] with colorectal cancer (CRC) third among most common tumour-sites [3]. In 54% of cases, cancer treatment side-effects include peripheral neuropathies, deconditioning, weight gain, and reduced functioning [4] with limitations in physical performance burdening survivors twice as much as those living without cancer [5]. There is no doubt therefore that management of the disease, and the effects of cancer treatment, will collectively impact healthcare resource allocation.

Evidence of health benefits from physical activity (PA) for people with cancer are compelling [5, 6] including reduced recurrence and mortality [6], improved functioning [7] and alleviating treatment-related side-effects such as pain, fatigue and anxiety [8–10]. The promotion of PA by health professionals (HPs) following cancer diagnosis is a 'teachable moment' to realise health outcomes and reduce healthcare costs [11–14]. While there is some evidence HPs promote PA in oncology [15, 16], recommendation rates at any stage of the cancer pathway reach only 29% by pan-disciplinary HPs [17] and 30% by oncology physicians [47] with PA training deficits cited as a barrier in both studies. Even when offered, the majority of PA advice by HPs does not align with current recommendations [17]. Thus, with professional PA advice imperfect, only 20% of people with CRC meeting exercise recommendations [18], and patients reporting a lack of guidance on being physically active [19] it is likely the advice delivered is not having its desired impact. However, data these conclusions are based on are self-report which can be prone to social desirability bias [15]. Therefore, it is of utmost importance to assess how successfully HPs are promoting PA by a method of enquiry that enables a fuller picture of behaviour. Consequently, the aim of this study was to use observational methodology to

determine whether, and how, HPs promote PA for people undergoing treatment for CRC.

METHODS

A non-participant observational study was conducted with a purposive sample of adults with CRC undergoing chemotherapy at a large cancer centre in London, United Kingdom. Observational data were collected in order to assess what PA support was delivered, in contrast to what was reported to be delivered. Interviews with patients and HPs were conducted to supplement observational data in highlighting similarities and differences between reported behaviour and observational data. HP-patient consultations were observed by the researcher (IV) and PA content was captured using a template and concurrent field notes. The template was developed through preliminary observations of consultations and in discussion with patients and HPs. PA was defined as any activity that requires energy expenditure through movement for example swimming or walking [20]. In order that commonalities and discrepancies between observed information conveyed by the HP and its perception by the patient could be ascertained, interviews with HPs and patients were conducted at the final assessment.

Cross-sectional, observational data were collected at each of the following four points: 1) before chemotherapy, 2) during chemotherapy, 3) midpoint of chemotherapy, and 4) 8 weeks following treatment completion. Observations consisted of consultations between HP and patients or interactions between HP, patients, and companions during intravenous chemotherapy. While the same patients were not observed at each time point due to resource limitations, this

maximised the number of patients involved in the data collection. It was not possible to collect demographic data of those observed due to pragmatic and ethical reasons. Concurrent field notes were used to describe the environment, people involved, activities and actions, timing and sequencing of events, goals and emotions expressed.

Patients who were non English speakers, had previous CRC or for whom PA was contraindicated (e.g. cardiac instability) were excluded. HPs observed included oncology consultants, registrars, specialist CRC nurses and chemotherapy nurses.

Eligible patients were identified by their HP and provided with written information. Verbal and written consent was obtained for observation of chemotherapy delivery and consultations respectively. To avoid a change in behaviour, participants were informed that we were observing the discussions on the topic 'what you can do to help yourself'. Patients from the final consultation point of end of treatment were invited to participate in semi-structured interviews. These were conducted with consenting patients to gain an understanding of perceptions and interpretations of PA advice received or delivered.

Interviews were conducted following completion of all the observations in order to avoid future participants becoming aware of the study's intent. Interviewees selected either face-to-face or telephone modalities according to personal preference and interviews were conducted using a topic guide which was developed and trialled with patients prior to usage. PA was discussed in relation to its definition, promotion, barriers during treatment and challenges by both HP and patients. Additionally, challenges faced by HPs in promoting PA as a self-management technique was included. Written informed consent was obtained for all interviews. Interviews were

audio recorded, transcribed verbatim, and anonymised. The number of observations/interviews was sufficient to achieve data saturation [21]

To enhance credibility and transparency of the findings by highlighting potential areas of influence, the researcher (IV) kept a reflexive account after each observation or interview in which she explored how her prior knowledge, attitudes and perception influenced the data analysis. The researcher was a female clinician with over 10 years' experience as a physiotherapist who viewed PA participation as important for people with cancer to maintain their wellbeing and promote recovery. Nevertheless, she had prior insight that HPs' inconsistently promote PA.

During the analysis codes and themes were identified in the observational and interview data using Framework Analysis (FA) [22]. FA is popular in healthcare research [23] as it permits concurrent analysis of observational and interview data [24]. A selection of interview transcripts were also coded by two experienced researchers (JA, VT) to enhance reliability and rigour [25]. Subsequently, observational and interview data were triangulated to highlight commonalities and discrepancies between observed PA advice delivery, and subjects' and HP's perception of delivery. The observations (at each time point) and the interview data were separately coded into themes. The interview themes that pertained to each observational time point were compared and contrasted with the observational data for commonalities and discrepancies. Observational themes (drawn from the analysis of field notes) at each time point are reported and complemented by illustrative quotes from the interview data. Contradictory results are discussed in detail in order to explore why discrepancies might exist.

The themes are reported using quotations from interview. Observation data are reported using the following codes: PC= Pre chemotherapy, CD= Chemotherapy delivery, MPC= Mid-point chemotherapy, EOT= End of treatment Consultation.

The study was granted ethical approval by the Research Ethics Committee (15/EE/04/34) and conducted in accordance with the ethical standards of the institution, and the 1964 Helsinki declaration [1].

RESULTS

Patient consent was provided to collect the following cross-sectional observational data PC (n=10), CD (n=6 sessions), MPC (n=10), mid treatment (n=10), and EOT (n=10) as described in Table 1.

Table 1: Detailed description of observations

Setting	Point in treatment pathway	Number of Observations	Duration per observation (minutes)
Pre-chemotherapy consultations (PC): HP led consultation prior to first chemotherapy cycle	Following surgery and prior to chemotherapy	10	60
Chemotherapy on Day Unit (CD): Delivery of chemotherapy	Chemotherapy delivery with multiple patients	6 sessions	120 minutes per session
Chemotherapy consultation Mid-Point chemotherapy (MPC): HP led consultation prior to next chemotherapy prescription	Following 8-12 chemotherapy cycles	10	10-30
End of treatment consultation (EOT): Conducted by HP following completion of treatment	8 weeks post chemotherapy	10	60

Following completion of all the observations, 16 interviews were undertaken with 8 CRC patients (Table 2) and 8 HPs (Table 3) lasting a maximum of 60 minutes (range =30-60).

Table 2: Interviewee characteristics: Patients

Number	Age	Gender	Diagnosis	Employment	Sequence of Treatment
1	56	Male	2013	Full time	Surgery (no stoma), radiotherapy, chemotherapy
2	66	Male	2015	Part-time	Surgery (no stoma) chemotherapy

3	51	Male	2015	Illness leave	Surgery (no stoma) chemotherapy
4	55	Male	2014	Full time	Surgery (no stoma) chemotherapy
5	67	Female	2013	Retired	Chemotherapy/radiotherapy, surgery (with stoma), chemotherapy
6	57	Male	2015	Illness leave	Surgery (no stoma), chemotherapy
7	69	Male	2015	Retired	Surgery (no stoma), chemotherapy
8	72	Female	2015	Retired	Brain radiotherapy, surgery to brain, surgery to colorectal (with stoma), chemotherapy

Table 3: Interviewee Characteristics: Health Professionals

Number	Profession	Oncology experience (years)	Gender
1	Chemotherapy nurse	3	Female
2	Colorectal senior nurse	10	Female
3	Colorectal senior nurse	2	Female
4	Colorectal senior nurse	2	Female
5	Consultant	5	Male
6	Consultant	20	Male
7	Chemotherapy senior nurse	20	Female
8	Chemotherapy nurse	9	Female

A number of themes emerged during analysis of the observational data augmented with interview data as follows:

PA is not routinely promoted prior to chemotherapy

Prior to chemotherapy, patient/HP consultations lasted between 45 and 60 minutes. The consultation was HP-led and delivered structured information including treatment delivery, side effects, and diet advice. Questions were encouraged throughout, however, patients appeared overwhelmed by the amount of information.

PA was not discussed routinely in the consultations prior to chemotherapy. HPs rarely raised the topic and it was only discussed in three of ten observations when patients asked about PA. Interview data also supports this finding.

> *"To be honest, I don't bring it up much unless they ask, I don't think I had thought about it to be honest" (#1 HP of PC consultation).*

HPs highlighted in the interviews that training in the delivery of PA advice and support to change behaviour had not been part of their training.

> *"We aren't trained to communicate in that way… it's a different way of talking with somebody, rather than saying these are all the side-effects you can get, just tell us and we'll manage it. It's a completely different skill so there is different training [needed]." (#7 HP Interview)*

Patients sought reassurance regarding safe types of PA during chemotherapy and were advised that:

> *"Exercise is good for managing fatigue" (#6 Reported speech of a HP prior to chemotherapy)*

Recommendations on the volume, intensity and duration of PA were not observed, except for advice to be conservative in their activities.

> *"I normally recommend to listen to their body, see how they feel during the chemotherapy. If they feel they can carry on with their activities, that's absolutely fine. But normally we recommend some gentler exercise to see how they get on". (# 1 HP interview)*

The interview findings showed patients perceived they were offered limited information about PA during treatment by HPs throughout their journey.

> *"Yeah, I think they did [mention PA], but it was just, you know, pretty basic, just get out and about and you know. I don't think it was really emphasised that much" (#2 Patient Interview)*

This lack of PA advice provision by HPs during consultations represents a missed opportunity to promote the role of PA in managing treatment side-effects and maintenance of fitness during chemotherapy. Moreover, whilst not observed, patients reported PA advice was given prior to treatment about avoiding swimming and heavy lifting activities, as this may cause peripherally inserted central catheters (PICC line) to dislodge or block. For one patient however, this message led them to avoid all PA during treatment.

> *"For six months I was happy not to do any physical exercise … [that could potentially] pull out my PICC line or interfere with the chemo in any way… I would have loved to have done it, but I just didn't want to test that PICC line" (#7 Patient interview)*

Rather than find alternative PAs which were safe to undertake with a PICC line, this patient chose not to do any PA, demonstrating a further missed opportunity.

PA promotion absent during delivery of chemotherapy

Advisory PA discussion was not observed during chemotherapy delivery other than on two occasions when HPs were observed advising patients to "*maintain your mobility*" or as a means to help unblock a peripheral line. Advice was not given on the type, volume or intensity of PA.

"Patients around me are being recommended by their nurses to get up, unplug their drip stands and go for a walk. No advice is given as to how long or how often or where to go". (#1 Observation using template CD)

Despite observations confirming HPs and patients interact during prolonged treatment times (~4-6 hours), none of the interactions were observed as being concerned with PA's role in managing common side-effects of treatment including fatigue, reduced mobility, or physical deconditioning. In addition, while the primary purpose of the day unit is the safe administration of chemotherapy, it was nonetheless interesting, but not surprising, to observe patients choosing to be sedentary for majority of time there with only low intensity PA observed.

Patient-to-patient conversations about PA were observed infrequently. Only one discussion was observed where a patient reported using PA as a coping strategy to manage treatment side-effects which included low energy.

"Chloe volunteered, 'I had a lack of energy, so I exercise, I go swimming and go to the gym, I just get on with life'… you have to control it, you have to have a positive thinking or it will control you'. It seems that Chloe has used exercise as a coping strategy, for her energy and for her sense of command over the situation". (#5 Observation CD)

Physical activity levels – an indicator of fitness for further chemotherapy

Observation of consultations between HPs (predominately doctors) and patients at the MPC followed a set structure which assessed the cancer treatment and the

resulting side effects. The HP used activity levels commonly assessed using the Eastern Cooperative Oncology Group performance scale [26] to determine fitness for the next chemotherapy treatment. Low activity/high sedentary behaviour is analogous to poor health and can risk the next chemotherapy cycle intervention resulting in treatment delays, reduced dosage or premature chemotherapy completion, and potentially poorer cancer outcomes.

"So … you're generally spending 50% of the day resting, I'm asking to know if I have to reduce the dose" (#4 Observation MPC)

This quote is from an example where a patient was sedentary for the majority of the day due to fatigue and deconditioning. The consequence was his treatment was delayed in order to allow for recovery, yet no advice was offered to facilitate their recovery.

Treatment side-effect discussions initiated by HPs at the MPC were task-focussed and formulaic in topic discussion and observed to include fatigue, deconditioning and nausea, all of which could negatively impact PA behaviour during treatment. Of the ten consultations observed, in only one did a HP offered advice on PA as a way to minimise treatment side-effects.

PA promotion is more prominent following completion of cancer treatment

At EOT, there was marked a change in the manner, style and content of HP-led consultations (mainly nurses). The specialist colorectal cancer HP equally lead the consultation suggesting a changed HP-patient relationship. Furthermore, PA was regularly discussed in the EOT consultation by the HP and the patient in the context of recovering from cancer treatment. Barriers to PA, including residual treatment

side-effects, were discussed and in many cases observation revealed HP and patients jointly identified ways to address them.

> *"'I can't run because of my feet; I feel cold, it's so cold'. The HP helped him to problem solve by reminding him of other activities which would also help with weight management including cycling, swimming to 'help him keep mobile and manage his weight'". (#4 Observation using a template at the EOT)*

HPs were also observed referring patients to relevant colleagues, including oncology physiotherapists, to offer further specialist support. The primary reason for referral to physiotherapy was a mutual acknowledgement that the person lacked confidence in returning to or increasing PA.

> *"The nurse suggested referring him to the local oncology physiotherapists for an assessment as it 'would give him the confidence again'" (#5 Observation EOT)*

Interviewed patients described the need to increase PA participation, including reducing cancer recurrence and weight management as part of a healthy lifestyle.

> *"Dominic's second goal is to reduce the risk of recurrence through eating healthily as weight gain and a poor diet can cause CRC. Yet, he mused, I had a good diet before so now it will have to be even better." (#4 summary of patient interview as recording failed)*

While PA type was often discussed, once again the consultations did not include specifics on frequency, volume and intensity.

DISCUSSION

HPs have been shown to be influential during the 'teachable moment' following a cancer diagnosis in supporting health behaviour change [27–29]. Furthermore, following a cancer diagnosis, people want more information concerning cancer treatment side-effects and strategies on management [30]. However, this study questions how successfully the opportunity is used in CRC.

Unlike others, our novel study focussed on the observable, rather than self-reported, practices of HPs in promoting PA during treatment and explored the relationship with patient perceptions of the information. The results demonstrated a general lack of PA promotion throughout the chemotherapy pathway with missed opportunities at all stages during treatment, in keeping with previous self-reported findings where HPs promoted PA in only 6-44% of cancer patient consultations [31, 32]. This is mirrored by the lack of patient recall of PA promotion during treatment in this study and others where only a third recalled advice [33]. Consequently, rather than utilising the cancer diagnosis as an opportunity to increase PA participation, this and other studies have shown this does not occur and may result in reduced participation [34].

It is clear from the results that PA is not being recommended as part of cancer care. Our data suggests a lack of HP confidence on PA advice. Our observational data confirmed that during MPC discourse about fitness for forthcoming chemotherapy cycles was prioritised, with very little opportunity to discuss other issues. The MPC were predominately led by the HP, and followed a predictable pattern of question and response meaning there was little deviation from the set pattern. Therefore, it was not obvious to the patient that the HP would enquire beyond their side effects and treatment planning, for instance PA. In contrast, PA was regularly discussed in the post treatment consultations which have been designed specifically to address a

wide range of patient concerns as part of the Recovery Package [35] including diet and exercise. This may explain the focus of the HPs on PA support and highlights the importance of context in patient and HP at this point. While it is promising that PA levels were discussed as part of the performance status assessment prior to and during treatment, the aim was to verify fitness for further chemotherapy, not as a teachable moment to use PA to minimise treatment side-effects. This missed opportunity may have occurred due to the treatment-orientated approach with HPs receiving little support to adopt a more holistic perspective of PA in the management of iatrogenic side-effects. Other studies support this interpretation, for example patient's symptoms were acknowledged but dismissed as expected chemotherapy side-effects [36, 37]. An alternative approach could be to consider treatment consultations as an opportunity for HPs to discuss treatment side-effects management with PA and thereby improve chemotherapy tolerance and treatment outcomes [33].

PA can play a significant role in maximising health benefits and promoting well-being as part of a self-management programme commonly used in long-term conditions alongside HP support [38, 39]. Two tools used to enhance PA levels in other long-term conditions could be deployed within the milieu of cancer-treatment culture. These include Brief Advice [40, 41], and self-management programmes [42]. Brief Advice for PA is a short verbal intervention addressing a patient's information needs, motivation and goal setting [13], while self-management programmes are more comprehensive combining education, exercise and problem solving [42]. Both approaches have been demonstrated to increase PA participation and improve health outcomes for people with cancer [13, 43].

It is noted, however, that investment in HP training would be required to use these methods as previous authors have reported the lack of PA promotion by HP is caused by inexperience [44], lack of confidence [16, 45], or a need for training [46]. HPs teaching PA as a self-management skill is not widespread practice with HPs often inexperienced in teaching these skills [44], findings also supported in our interview data.

There are substantial challenges, therefore, in implementing both these HP-led approaches which will need to be factored into future efficacy studies. PA remains an area where patients can take the lead in their care with support and encouragement from HPs when suitable and person-centric information is delivered.

LIMITATIONS

This study used observation and interview methods successfully in investigating how PA is discussed during treatment. However, this approach was not without limitations. While key time points were identified for observation of clinical practice, the data were cross-sectional and not longitudinal. Therefore, the results are not comprehensive of the whole CRC pathway, as highlighted by interviewees reporting that PA advice was delivered in non-observed settings. While our sample was sizable we must acknowledge it was nevertheless one of convenience and subject to selection bias. Applicability of our results should therefore take this into account and be limited to patients with CRC undergoing curative chemotherapy treatment in an established cancer centre. In addition, the amount of observational data available for analysis is predicated on the timescale of the phenomenon under observation. We observed interactions between clinicians and patients which were relatively short in duration [approx. 20 minutes]. We acknowledge therefore that our methods limited the depth of analysis we were able to undertake.

RECOMMENDATIONS

This was a small scale qualitative study, therefore generalisations should be scaled accordingly. However, confidence in the data is derived from the congruence between our findings and those of other studies. Our findings identify the inconsistent message being delivered to patients currently. The onus is on HPs, therefore, to examine their practice in promoting PA. Further research is needed to conduct implementation studies to improve PA promotion practice and assess the impact on PA participation.

CONCLUSIONS

Findings from our study show that PA was inconsistently promoted to people with CRC during treatment. Missed opportunities occurred including the assessment of PA levels to determine fitness for further chemotherapy which did not result in HP promotion of PA. On completion of treatment, PA discussion in consultations was more prominent. However, any reference to types of PA or dose remained lacking. Further investigation is needed to enhance patient's ability to take a greater role in their care via HP promotion of PA during treatment. PA has the potential to be used by patients as a strategy to manage treatment side-effects and maintain fitness throughout treatment, however, our findings suggest it is not fully recognised.

Conflict of Interest

Conflict of Interest: The authors declare that they have no conflict of interest. The authors retain full control of all primary data and are willing for the journal to review their data if requested.

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